STATE TRAUMATIC BRAIN INJURY

ADVISORY BOARD

HANDBOOK FOR MEMBERS

Prepared by the State of Hawai`i Department of Health
Developmental Disabilities Division
Developmental Disabilities Services Branch

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I. INTRODUCTION

This Handbook provides members of the State Traumatic Brain Advisory Board **(STBIAB)** with information on the Board's origins, mandates and achievements related to traumatic brain injury (TBI).

TBI is defined as *"an occurrence of injury to the head (arising from blunt or penetrating trauma or from acceleration-deceleration forces) that is associated with any of these symptoms or signs attributed to the injury – decreased level of consciousness, amnesia, other neurologic or neuro-pyscholgic lesions, or death (Centers for Disease Control and Prevention, 1995)."*

II. BACKGROUND

- 1996 U.S. Congress passed legislation (TBI Act of 1996) to encourage State governments to form TBI advisory boards, conduct studies, foster innovative programs, and improve access to a comprehensive, coordinated system of care for persons with TBI.
- 1996 BIA-HI met with the Department of Health Director and Hawai`i State legislators to get support for TBI legislation in Hawai`i.
- 1997 Hawai`i State legislature (through lobby efforts by BIA-HI and individual advocates) passed a law to set up the State Traumatic Brain Injury Advisory Board to advise the Director of Health.
- 1997 Act 333 was introduced and passed by the Hawai`i State Legislature with $50,000 in appropriations for use as federal matching funds.

ACT 333 – A Bill for an Act Relating to Traumatic Brain Injury

The legislature finds that every year 1.9 million Americans experience traumatic brain injury. About half of these cases result in short-term disability, and approximately 52,000 people die as a result of these injuries. Of those who survive, 70-90,000 endure life-long debilitating losses of function. An additional 2,000 will exist in a persistent vegetative state.

Traumatic brain injury is the leading cause of death and the leading cause of disability in children and young adults. Motor vehicle accidents cause one-half of all traumatic brain injuries; falls account for 21%; assaults and violence 12%; and sports and recreation 10%. Further, child abuse accounts for 64% of infant head injuries.

The legislature further finds that the physical consequences of brain injury include impairment of speech, vision and hearing loss, headaches, muscle spasticity, paralysis, and seizure disorders. The cognitive consequences of brain injury include memory deficits, limited concentration, impaired perception and communication, and difficulties with reading, writing, planning and judgment. The psycho-social-behavioral-emotional consequences of brain injury include fatigue, mood swings, denial, anxiety, depression, lack of motivation, and problems with interpersonal skills.

A survivor of a severe brain injury typically faces 5 to 10 years of intensive treatment, with estimated lifetime costs exceeding $4 million. Nationally, the direct medical costs for treatment of traumatic brain injury have been estimated at more than $4 billion per year. The total economic costs of brain injury have been estimated at $25 billion per year.

The purpose of this Act is to increase public awareness of the consequence of brain injury to not only prevent such injuries, but to enhance the recovery process for all brain injury survivors by establishing a traumatic brain injury advisory board within the department of health to develop and implement a comprehensive plan by encouraging public and private partnerships and private sector responses.

This Act shall take effect on July 1, 1997. (Approved July 2, 1997)

Hawai`i Revised Statutes (HRS), Volume 6, Title 19, Chapter 321

[§321-28] Traumatic brain injury advisory board. There is established within the department of health the traumatic brain injury advisory board. The advisory board in consultation with the neurotrauma advisory board, shall advise the department in the development and implementation of a comprehensive plan to address the needs of persons affected by disorders and disabilities that involve the brain. Further, the advisory board in consultation with the neurotrauma advisory board, shall advise the department of the feasibility of establishing agreements with private sector agencies to develop services for persons with brain injuries.

The advisory board shall consist of at least 9 members who shall be appointed by the director of health in accordance with section 26-35. The director of health shall designate a member to be the chairperson of the advisory board. The director or designee shall serve as an ex officio nonvoting member of the advisory board. The members shall serve for term of 4 years; provided that upon the initial appointment of the members, two shall be appointed for a term of 1 year, two for a term of 2 years, two for a term of 3 years and three for a term of 4 years. In establishing the advisory board, the director of health shall appoint at least:

(1) Two members representing private sector businesses that provide Services for brain injured persons;

(2) Two survivors of traumatic brain injury; and

(3) One member representing trauma centers that provide services for brain injured persons.

The members shall serve without compensation but shall be reimbursed for actual expenses, including travel expenses, that are necessary for the performance of the duties.

III. MISSION OF THE STBIAB

The mission of the State Traumatic Brain Injury Advisory Board is to ……...

- advise the Department of Health in the development and implementation of a comprehensive plan to address the needs of persons affected by disorders and disabilities that involve the brain;

- advise the Department of the feasibility of establishing agreements with private sector agencies to develop services for persons with brain injuries;

- provide leadership and participation in the development and implementation of the comprehensive plan by encouraging public and private partnerships and private sector participation.

IV. GOALS OF THE STBIAB

In June 2003, members of the STBIAB with the assistance of a facilitator, through a strategic planning process, identified 4 priorities for the Board to consider.

- Professional community service providers (social/human service workers, churches, police/fire, insurance adjusters, immigrant services – generally those that offer social support from birth on) will be able to define TBI, its causes, possible impacts, access to services, and the need for public policy change and funding.

- Data collection/registry/needs assessment: a regular collaborative TBI related needs and resource assessment is conducted with sensitivity to women, children, and native Hawai`ian and other minority populations. Surveillance to gather injury causation data.

- Improve access to services (transportation, counseling, cognitive training, housing, acute care, etc.).

- Improve funding for services.

A follow-up Strategic Planning Session was held in September 2003 to prioritize the four above areas. With the assistance of the facilitator, a matrix was used rate the four areas – a) whether it was do able, b) within resources, c) no training needed, d) funding available, e) not duplicated by others, and f) benefits TBI survivors today. The results in order of importance and priority were:

- Professional Awareness
- Improve services
- Improve funding
- Registry

The group decided on combining 'Improve Services' and 'Improve Funding' into one area as they were very similar and related. Thus the two priority areas identified were:

- **Professional Awareness**

- **Increasing Funding and Services**

Subcommittees with lead persons were formed to address these two priority areas. And the next task and challenge will be for members to develop goals, objectives, activities, and timelines for each area.

V. BY-LAWS OF THE STBIAB (Revised April 17, 2003)

The following by-laws are guided by the Sunshine Law and HRS Chapter 92 (see Appendix A).

Article I. Name
The name of this group shall be the State Traumatic Brain Injury Advisory Board (STBIAB).

Article II. Establishment
This board was established in 1997 by Act 333, First Regular Session of the Nineteenth Legislature of the State of Hawai`i.

Article III. Purposes
The Advisory Board, in consultation with the neurotrauma advisory board, is to advise the Hawai`i State Department of Health in

1. The development and implementation of a comprehensive plan to address the needs of persons affected by disorders and disabilities that involve the brain and
2. The feasibility of establishing agreements with private sector agencies to develop services for persons with brain injuries. (321-28, HRS)

Article IV. Members
1. **Appointment**. The director of health shall appoint the members.

2. **Composition**. The advisory board shall consist of at least nine members. The director of health or a designee shall serve as an ex officio non-voting member of the advisory board. The director of health shall appoint to the Board at least:

    a. Two members representing private sector businesses that provide services for persons with brain injuries;
    b. Two survivors of traumatic brain injuries; and
    c. One member representing trauma centers that provide services for persons with brain injuries (321-28, HRS).

    The director of health also may appoint additional non-voting members to the advisory board to assist it in accomplishing its tasks.

3. **Terms**. The voting members shall serve of a term of four years, provided that upon the initial appointment of the voting members, five will be appointed for a term of one year, five for a term of two years, five for a term of three years, and six for a term of four years.

4. **Compensation**. The members shall serve without compensation but shall be reimbursed for actual expenses, including travel expenses that are necessary for the performance of their duties.

5. **Resignations**. A member may resign by delivering a written resignation to the director of health. The resignation shall be effective upon receipt unless it is specified to be effective at some other time.

6. **Vacancies**. The Board will notify the Director of Health of any vacancies on the board and request that a new member be appointed.

7. **Conflicts of Interest**. Members of the Board are prohibited from taking action when they have a conflict of interest as defined in Chapter 84, HRS.

8. **Removal.** The board may ask the Director to remove a member for cause. Cause shall mean a court order for mental in-competency or a felony conviction.

Article V. Meetings

1. **Meeting Notices**. The Board shall give written public notice of any regular, special, or rescheduled meeting. The Board shall file the notice in the office of the lieutenant governor at least six calendar days before the meeting. (92-7, HRS)

2. **Agendas**. The written public notice of a meeting shall include an agenda that lists all of the items to be considered at the meeting and the date, time and place of the meeting. (92-7, HRS)

3. **Changes in Agenda**. The Board shall not change the agenda, once filed, by adding items without a two-thirds recorded vote of all voting members to which the Board is entitled; provided that no item shall be added to the agenda if it is of reasonable major importance and action thereon by the board will affect a significant number of persons. Items of reasonably major importance not decided at a scheduled meeting shall be considered only at a meeting continued to a reasonable day and time (92-7 HRS).

4. **Quorum**. The presence of a majority of the voting members to which the Board is entitled shall constitute a quorum to do business. (92-15, HRS)

5. **Voting**. Each member entitled to vote shall have one vote. Voting by proxy shall not be permitted. When a quorum is present, a position shall be carried by the majority of the members present.

6. **Minutes**. The Board shall keep written minutes of all meetings that give a true reflection of the matters discussed at the meeting and the views of the participants. The minutes shall include a) the date, time and place of the meeting; b) the names of the members of the Board recorded as present or absent; c) an account of the substance of all matters proposed, discussed, or decided; d) a record, by individual voting member, of any votes taken; and e) any other information that any member requested be included in or reflected in the minutes. (92-9, HRS)

7. **Permitted Interactions of Voting Members Outside of Meetings**. Interactions of voting members outside of the meetings shall be governed by Section 92-2.5, HRS.

8. **Meetings by Videoconference**. The board may hold meetings by videoconference, as described in Section 92-3.5, HRS.

9. **Annual Meeting.** The first meeting of each calendar year shall be the annual meeting.

10. **Regular Meetings**. The Board shall meet at least quarterly and at other times as necessary.

11. **Special Meetings**. Special meetings for business that cannot wait until the next regular scheduled meeting of the Advisory Board may be called by the chair or by a majority of the voting members of the Board.

12. **Attendance at Board Meetings**. Voting members are expected to attend Board meetings whenever possible. Voting members who are unable to attend a meeting should notify a designated staff person of the Department of Health. The chair of the board and/or administrative staff shall maintain records of attendance. Any member absent from three consecutive meetings or five meetings during a year will be presumed unable to participate on the board. The Director may then move to appoint a replacement to the board. The Chair and/or DOH representative shall inform the affected board member in writing of action taken.

13. **Open Meetings**. Every meeting of the Board shall be open to the public and all persons shall be permitted to attend all meetings, provided that the removal of any person or persons who willfully disrupt a meeting to prevent or compromise the conduct of the meeting shall not be prohibited. The Board shall also afford all interested persons an opportunity to present oral or written testimony on any agenda item (92-3, HRS).

14. **Meeting Procedures**. The Board shall conduct its meetings according to Robert's Rules of Order (newly revised), unless it decides to operate according to alternative set of rules.

Article VI. Officers

1. **Enumeration**. The officers of the Board shall be a chair, a vice chair, and a Secretary.

2. **Appointment of Chair**. The Director of Health appoints the chair of the Board.

3. **Election and tenure of vice chair and secretary.** The vice chair and secretary shall be elected annually by the voting members at the annual meeting, or at the special meeting held in lieu thereof. The Board at any meeting may fill the vice-chair vacancy and the officer so elected shall serve for the remainder of the term of his/her predecessor, subject to all other provisions of these by-laws. The vice-chair may resign by delivering a written letter of resignation to the chair.

4. **Duties of Chair**. The chair shall be responsible for formulating the agendas for and conducting the meetings of the board. The chair may appoint task forces and committees and perform such other duties as designated by the Board.

5. **Duties of Vice Chair**. The vice chair shall perform the chair's functions in the absence of the chair and such other duties as may be decided by the Board.

6. **Duties of Secretary**. The secretary shall supervise the production of minutes that describe all votes and proceedings of meetings of the Board. The secretary shall perform other duties as described by the Board

Article VII. Committees

1. **Creation of Committees**. The Board may create committees with specific tasks as necessary to accomplish its work. Those committees shall be subject to the requirements of Section 92-2.5, HRS.

2. **Committees act in Advisory Capacity to the Board.** Committees shall make recommendations for action to the Board, which must be approved by the Board prior to implementation.

3. **Committee Membership**. The Chair may appoint persons who are not Board members to serve on task forces and committees.

4. **Open Meetings**. Meetings of the Board's committees and task forces shall be open to the public.

Article VIII. Amendments
The Board can make, amend, or repeal these by-laws by an affirmative vote of the majority of the voting members appointed to the Board. Changes in the by-laws will not take effect until the next meeting of the Board.

Article IX. Conflicts with State and Federal Statutes and Administrative Rules
When a provision of these by-laws conflicts with State or Federal Statutes or Administrative Rules, the relevant statute or rule supersedes these by-laws.

VI. COMPOSITION OF THE STBIAB

A. CURRENT MEMBERS

(For contact information, see Appendix B)

1. **Cori Fujiura,** Rehab. Hospital of the Pacific (O`ahu)
2. **Tom Harding**, Craine Institute of Neuropsychology & Rehabilitation, Inc.,*Vice Chair* (O`ahu)
3. **Dr. Patricia Heu,** Dept. of Health, Children with Special Health Needs Branch (O`ahu)
4. **Tony Hunstiger,** *Chair* (O`ahu)
5. **Douglas Hupp,** Survivor (O`ahu)
6. **Hal Kahikina,** Survivor (O`ahu)
7. **Kelly Knudsen,** Dept. of Education (Kaua`i)
8. **Reta Manriquez,** Survivor (Kaua`i)
9. **Malexi McPhee,** Survivor, *Secretary* (O`ahu)
10. **Dr. Thomas O'Callaghan,** Queen's Medical Center Trauma Services (O`ahu)
11. **Dr. Robert Sloan,** Physiatrist (Hawai`i)
12. **Lee Taylor,** Survivor (Maui)
13. **Mary Wilson-Isley,** Brain Injury Association – Hawai`i (O`ahu)
14. **Kawena Young,** Survivor (O`ahu)

B. PAST MEMBERS

1. Lyna Burian, Family Member
2. Fred Fortin, HMSA
3. Marsha Joehansen, Family Member
4. Dr. David Kim, Rehab. Hospital of the Pacific
5. Linda Kushi, Family Member
6. Ian Mattoch, Attorney
7. Stephanie Thomson, Queen' Medical Center Trauma Services

VII. TBI PLANNING GRANT

In 1999, the Hawai`i State Department of Health (DOH) applied to the Maternal and Child Health Bureau (MCHB) for a Traumatic Brain Injury Planning Grant (CFDA #93.234B) to build core capacity to address service needs and investigate resources for persons with Traumatic Brain Injury (TBI) in the State. The Grant was approved for the period from August 1, 1999 to March 31, 2001.

The MCHB is one of three federal agencies charged with implementing TBI service programs as a result of the congressional enactment of Public Law 104-166 in July 1996. In FY 1997, the MCHB established a program of grants for States to conduct demonstration projects to improve access to health and other services for the assessment and treatment of traumatic brain injury.

In conjunction with the intent of the MCHB grant program, the goals of Hawai`i's grant were to 1) conduct a statewide needs and resource assessment, 2) develop a statewide plan, 3) strengthen the role of the State Traumatic Brain Injury Advisory Board (STBIAB), and 4) build Hawai`i's capacity to address the services of persons with traumatic brain injury.

In the early 1990's, the state began efforts to obtain information on the status of services for persons with TBI and to have meetings regarding needs and a coordinated service delivery system. The State Commission on Persons with Disabilities produced a status report stating that services were few to this population and data regarding the number of persons with TBI and their needs were very limited.

Over the years, data on this population continued to be limited and services fragmented with limited collaboration among agencies. A statewide comprehensive system was needed to provide, manage and monitor services for persons with TBI. The Department of Health assumed a key leadership role with the establishment of the State Traumatic Brain Injury Advisory Board in 1997. That year, the legislature passed Act 333 which established the Board to advise the department on the development and implementation of a comprehensive plan to address the needs of persons affected by disorders and disabilities that involve the brain and the feasibility of establishing agreements with private sector agencies to develop services for persons with brain injuries. With the initiation of the board, there was a new and established venue for collaboration among agencies.

The Planning Grant's primary purpose was to establish a collaborative infrastructure, support communication among the participating agencies and individuals in order to implement and complete a needs and resource assessment, and devise an action plan to create a statewide system of comprehensive and coordinated services for persons with TBI.

GOALS AND OBJECTIVES:

The goals and objectives of the planning grant project were built on the earlier work done by community agencies and the Commission of Persons with Disabilities. The goals were also in keeping with the intent of the MCHB grant program.

The **Goals** of the planning grant were to:

1) Complete a Needs and Resource Assessment

2) Develop a Statewide Action Plan

3) Strengthen the Role of the State Traumatic Brain Injury Advisory Board and

4) Build Hawai`i's Capacity to Address the Services of Persons with TBI.

The **Objectives** of the grant were:

Year One Objectives:

1. The DOH and designated staff person will assume responsibility for and assist in planning activities for the completion of the needs and resource assessment during the grant period.

2. The STBIAB will be organized, actively engaged and committed to the needs and resource assessment and planning activities during the grant.

3. DOH staff and the STBIAB will assure that the Statewide Needs and Resource Assessment is completed during the grant period.

Year Two Objective:

1. DOH staff and the STBIAB will assure that the statewide action plan is completed during the grant period.

The Objectives of **a TBI Action Plan**

1. Educate about TBI
2. Expand Resources/Funding/Sustainability
3. Improve Quality of Care/Services

VIII. TBI IMPLEMENTATION GRANT

The Developmental Disabilities Division (DDD) of the Hawai`i State Department of Health through the Health Resources Administration Maternal and Child Health Bureau oversees the Hawai`i State TBI Implementation Grant (CFDA #93.234A) which runs from April 1, 2002 to March 31, 2005. The Grant addresses 2 areas of concern identified during the 1999-2001 Hawai`i TBI Planning Grant process:

1. Education about TBI is lacking: public information about TBI and its incidence is limited. An assessment conducted in Hawai`i showed most people were not acknowledgeable about TBI. Perceptions of service access by persons with TBI and their families and the availability of information about best practice among service providers was inconsistent. There is a consensus among stakeholders that persons with TBI and their families need to access information about services/resources to make informed choices.

2. Quality of care and services are lacking: Hawai`i's TBI Planning Grant survey evidenced that persons with TBI, as a group, have a great range of community living needs that are not being met by a fragmented services system across the island chain. Those living in rural areas an the outer islands of the State have even greater difficulty obtaining information and needed support services.

GOALS AND OBJECTIVES

The aim of the Implementation Grant follows the 2001 Action Plan for TBI, to namely, enhance access to comprehensive and coordinated TBI services and reflect Healthy People 2010 goals.

Goal 1. *Increase the quality, availability, and effectiveness of educational and community-based programs designed to prevent disease and improve health and quality of life for persons with TBI.*

For individuals with TBI and family, emphasis is directed to making information on services and resources accessible through different options: print, telephone and website. The availability of resource persons on the outer islands is a priority. Community groups and organizations will obtain education on TBI through a speaker' bureau to build public and community support for TBI initiatives. For professionals, a cadre of instructors will be trained to provide local capacity for ongoing training in TBI through the university system. Continued development of the STBIAB is also addressed to build teamwork and organizational effectiveness.

Goal 2. *Improve access to comprehensive, high quality health care services.*

While current legislative advocacy is expected to result in sustained funding for services and a Medicaid Waiver to maximize resources, the quality of services must also be addressed. The DDD and the STBIAB will collaborate with Pacific Basin Rehabilitation Research and Training Center and community members (including individuals with TBI and family) to develop a process to evaluate quality of services provided to individuals with TBI and family by healthcare and service organizations. The availability of information to individuals with TBI and family regarding multiple measures of a provider's services will enable more informed choices by service recipients, and create incentive for providers to improve the quality of their services. Focus is also given to developing a mechanism for obtaining ongoing feedback from individuals with TBI and family.

IX. NEUROTRAUMA SYSTEM

Act 160, signed into law as HRS Chapter 321H on June 7, 2002, establish mandates for matters relating to Neurotrauma.

- Department of Health shall develop, lead, administer, coordinate, monitor, evaluate, and set direction for a comprehensive system to support and provide services for survivors of neurotrauma injuries.

- There is established within the Department a Neurotrauma Advisory Board to advise the director in implementing this chapter.

- There is established the Neurotrauma Special Fund to be administered by the Department with advisory recommendations from the Neurotrauma Advisory Board.

The State TBI Advisory Board, in consultation with the Neurotrauma Advisory Board

- Shall advise the Department of Health in the development and implementation of a comprehensive plan to address the needs of persons affected by disorders and disabilities that involve the brain.

- Shall advise the Department of the feasibility of establishing agreements with private sector agencies to develop services for persons with brain injuries.

- And the Neurotrauma Advisory Board by statutes is required to have a member representing the State TBI Advisory Board (Chapter 321H-3, HRS).